

# **FOLLOW UP TO THE THEMATIC SEGMENT FROM THE 49<sup>TH</sup> PCB MEETING**

**What does the regional and country level data tell us, are we listening, and how can we better leverage that data and related technology to meet our 2025 and 2030 goals**

**Additional documents for this item:** UNAIDS/PCB (49)/21.33; UNAIDS/PCB (49)/21.34; UNAIDS/PCB (49)/CRP2

**Action required at this meeting:** The Programme Coordinating Board is invited to:

40. *Take note* of the background note (UNAIDS/PCB (49)/21.34) and the summary report (UNAIDS/PCB (50)/22.7) of the Programme Coordinating Board thematic segment on “What does the regional and country level data tell us, are we listening, and how can we better leverage that data and related technology to meet our 2025 and 2030 goals?”;
41. *Request Member States* to:
  - a. Strengthen people-centred, confidential national patient monitoring and case surveillance systems, including the use of periodic surveys of key populations, and leverage disaggregated data to identify location- and population-based gaps in services;
  - b. Collaborate with affected communities, strengthen their capacity and dedicate sufficient financial resources for robust community-led monitoring of the affordability, availability, acceptability and quality of services, and ensure the use of complementary data from community-led monitoring in national and subnational programme planning, management and evaluation;
  - c. Develop and implement plans for the collection of data on societal enablers that generate national understanding of legal, policy and social barriers faced by people living with HIV and other people in need of HIV services, and guide efforts to remove such barriers, including through the establishment of enabling legal and policy environments for rights-based HIV services that address inequalities;
  - d. Ensure that UNAIDS has sufficient financial resources to support countries to develop and implement robust systems for the monitoring and evaluation of national HIV responses;
  - e. Report data to UNAIDS through the Global AIDS Monitoring on an annual basis to monitor the implementation of AIDS responses;
42. *Request the Joint Programme* to:
  - a. Support countries to incorporate evidence-informed national targets that reflect the scope and granularity of the 2025 targets laid out in the Global AIDS Strategy into their national HIV response plans and monitor progress against these targets;
  - b. Further support countries to develop and implement plans for the collection of data for HIV service coverage, societal enablers, integration, financing and impact, and support efforts to establish enabling legal and policy environments for quality and comprehensive HIV services that address inequalities;
  - c. Continue to regularly collect data from countries, make those data available to stakeholders and produce detailed reports to the international community on global progress towards 2025 and 2030 targets;

**Cost implications for implementation of decisions:** none

**THEMATIC SEGMENT: WHAT DOES THE REGIONAL AND COUNTRY LEVEL DATA TELL US, ARE WE LISTENING, AND HOW CAN WE BETTER LEVERAGE THAT DATA AND RELATED TECHNOLOGY TO MEET OUR 2025 AND 2030 GOALS?**

1. Peter Ghys, Director of Strategic Information, UNAIDS, moderated the thematic segment. He noted that the thematic segment provided an opportunity to discuss how the availability and strategic use of high-quality, timely and reliable data can help end AIDS as a public health threat by 2030. He said data had been the bedrock of progress against the epidemic, but data collection was uneven across countries and decision-makers did not always heed the data. The focus currently was on ensuring that timely and accurate data are available to national responses and that they are utilized for impact. Introducing the agenda for the day's segment, Mr Ghys noted that the meeting would hear many examples over the course of the segment that illustrate how AIDS-related data have helped countries achieve results in their responses and improve the lives of those living with and affected by HIV. In addition, the session would focus on identifying gaps and challenges to collecting and effectively utilizing this data, including stressing the importance of confidential and ethical use of data.
2. Mr Ghys introduced the first speaker, Juliet Cuthbert-Flynn, State Minister of Health and Wellness, Jamaica. She said new HIV infections in her country had declined by 42% between 2004 and 2019. But more had to be done: 5000 of the 32 000 people living with HIV (PLHIV) were unaware of their HIV status, for example, and HIV prevalence among gay men and other men who have sex with men remained very high. The most recent (2020) Stigma Index showed that accepting attitudes towards PLHIV were still very low, and 10% of PLHIV reported experiencing stigma or discrimination from health-care workers in the previous 12 months. Those were unacceptable figures, the State Minister said.
3. Ms Cuthbert-Flynn shared some of the actions taken by her government. A national human rights mass media campaign had been developed in 2020 and her ministry was advocating for policy and legislative reforms, including HIV-specific legislation, she told the meeting. The National Family Planning Board maintained a partnership with the Jamaica Council of Churches to address stigma and discrimination within faith-based organizations. The capacity of labour offices was being strengthened to enforce national workplace policy provisions, including HIV-related protections. Partnerships with communities were growing and the Jamaican government was committed to have a cultural, legislative and policy framework that can help end the epidemic, she said.
4. Marijke Wijnroks, Chief of Staff, Global Fund to Fight AIDS, Malaria and Tuberculosis, said the HIV community had spearheaded the use of data to shape public health policies and practices. She said the Global Fund consistently used those data to inform funding decisions across its entire funding cycle and for course corrections. During COVID-19, the Global Fund had benefited from earlier investments in national information systems, which could track service disruptions and recoveries. The Global Fund was one of the primary funders of in-country data systems-building and -strengthening, Ms Wijnroks said.
5. UNAIDS was the primary technical partner of the Global Fund for collecting, analysing and using data at all levels, she told the meeting. It routinely used UNAIDS estimates, Global AIDS Monitoring and other data to guide key funding decisions, including country eligibility, investment cases for replenishment, country allocations and priority setting. At country-level it also worked with UNAIDS around country-specific grant issues, while principal recipients in countries worked closely with UNAIDS and partners to review and evaluate the investments. She listed a range of other respects in which the Global Fund and UNAIDS worked closely together around the collection,

analysis and use of quality HIV-related data.

6. Sara Davis, senior researcher and lead of the Digital Health and Rights Project at the Global Health Centre at the Graduate Institute, Geneva, spoke about the populations left "uncounted" by many public health systems, and she said the ways in which data were collected often still missed key populations, which affected funding decisions. This was especially relevant in the context of diminishing funding for HIV. She reminded, though, that health data are not neutral but are shaped by historical disparities, policies and biases. Achieving better data also required addressing inequalities. There were large gaps in data for key populations even though community-led organizations often have relevant data about the communities they serve. She noted that the ostensible lack of data meant that governments could ignore or play down the needs and realities of certain populations; "absence of evidence" was used as "evidence of their absence".
7. Referring to historical inequalities between the global North and global South, Ms Davis said some donors were pressuring countries to produce data on key populations. This sometimes helped, but it could also backfire: some health agencies might produce estimates and other data, but not publish the results, while others might inflate estimates in the hope of attracting more funding. Some countries used the processes in ways that could put people at risk and expose them to harassment, violence and arrest, she added.
8. Countries were caught in a "data paradox", Ms Davis said: political power shaped both the data that are available and the data that are lacking. One way forward was to invest more in collecting data from the ground up and to use community-engaged research to do so. Ms Davis shared an anecdote from a Caribbean country which had lost its data about key populations when donor funding ended. A Caribbean community of vulnerable populations stepped in, worked with social scientists to design rigorous research methods, built capacity and accessed funding. It has now produced solid new data for six countries, though these have not been published. When people participate in producing knowledge about themselves, they see how their efforts help promote the common good, they exercise agency and they gain dignity, Ms Davis emphasized. Through community-engaged research, people can create transformative change together and learn together with those we have been failing to reach.
9. Winnie Byanyima, Executive Director of UNAIDS, said the world was undergoing a data revolution. This was both exciting and potentially dangerous because the data could be used to end inequalities, but also to consolidate power and oppress people. Near-real-time estimates were showing the inequality among countries in the COVID-19 pandemic, but they also had limitations, she cautioned, because they did not show who was being missed by interventions and why this was happening. She reminded that the Global AIDS Strategy emphasized the importance of addressing inequalities for reaching the 2030 goal of ending AIDS and called on countries to collect and use data to reduce inequalities.
10. Ms Byanyima also underscored the importance of community-led monitoring, especially to understand the experiences and needs of marginalized populations when they seek health-care services. Community-led organizations were best-placed to collect those kinds of data. She also underscored UNAIDS's strong working relationships with countries, the Global Fund, PEPFAR and other partners around the collection and use of data in countries. She said the UN system was best at doing some things, communities at others, and governments at yet others. To end AIDS, they all have to work together.

11. Shannon Hader, Deputy Executive Director, UNAIDS, summarized the background note (UNAIDS/PCB (49)/21.34) that had been prepared for the thematic segment. She said the HIV response had yielded one of the most comprehensive, granular and timely data systems in global health and development. The data were used not just for reporting or tracking, but also informed major policy and programme shifts and innovations: they served as a bedrock of the HIV response. However, the collection and use of data were uneven, she noted and stressed the importance of engaging communities as partners.
12. Turning to what data revealed about the HIV response, Ms Hader said they showed big successes along with ongoing gaps and inequalities. Forty countries were on-track to achieve a 90% reduction in deaths due to AIDS by 2030, and 35 were on-track to reduce new HIV infections by at least 90%. But none of the 2020 Fast-Track targets had been achieved globally and no region had met the Fast-Track target of reducing new HIV infections by at least 75%. Combination prevention was still underused.
13. Ms Hader said data continued to expose the many inequalities that prolonged the epidemic. Social and structural barriers were blocking service uptake and increasing HIV vulnerability. For example, violence against women was linked to delayed HIV treatment uptake and worse outcomes for women living with HIV. In sub-Saharan Africa, 6 in 7 new infections among adolescents were among adolescent girls. Poverty, lack of education and discrimination were also impeding access to health and HIV services, she explained, citing evidence that uptake of voluntary medical male circumcision tended to be higher for wealthier men. When countries and governments have heeded the data, high coverage of HIV services have been achieved. Data visualizations were helping countries understand and apply insights in programmes, she said. Data capturing the epidemic's disproportionate impact on adolescent girls and young women had spurred stronger action.
14. Ms Hader also referred to the large treatment gap for children compared with adults living with HIV: 74% compared with 54%. About 800 000 children were not diagnosed and not on treatment. This gap had been hidden until accurate age-disaggregated data had been collected. More nuanced data were also suggesting new ways to reach men. Study data from Malawi, for example, showed that 70% of men in need of HIV testing had visited health-care facilities in the previous year, but only 7% had been offered an HIV test. Data also showed the extent and impact of punitive and discriminatory laws on the HIV response, she noted. These kinds of information can change how services are designed and delivered, so everyone can benefit.
15. Ms Hader told the meeting that UNAIDS collected and analysed vast amounts of data and supported countries to gather and use the data effectively. It also routinely reported on progress and gaps in the HIV response. Looking ahead, she noted the need for sustainable and routine national health information systems, as well as focused surveys that reach people who are left behind. Community-generated data should become a pillar of HIV response information systems and data should be geolocated and include age, sex and other relevant metrics, she said. At the same time, confidentiality of individual patient data, risk, behaviours and other private information must be guarded. Ms Hader reminded the meeting that "data do not speak, people speak". It was crucial to examine the data and test assumptions so that effective solutions could be crafted and implemented.
16. In discussion, speakers highlighted the Joint Programme's investments in sex- and age-disaggregated data that have helped identify and respond to important patterns and trends. When overlaid with socioeconomic and other data, the information could be used to focus and modify interventions, they said. However, many countries still

underestimated the sizes of key populations, which had major implications for their HIV programmes.

17. The meeting heard a compelling summary of data related to adolescent girls in southern Africa, including low levels of condom use, poor knowledge about HIV, and high levels of gender-based violence, including sexual violence. Some members shared updates about their collection and use of HIV-related data, including the integration of data into single platforms and the use of protected registers that support effective HIV treatment distribution, including for itinerant people living with HIV.

### **Panel 1. Leveraging data to fill gaps in HIV service coverage**

18. The first panel focused on the ways in which improved data and analyses were being used to enhance coverage and results of HIV services.
19. Emanuel Zenengeya, Head of Planning for Malawi's National AIDS Commission, spoke on the use of triangulated data in his country's HIV response. Malawi was using multiple data sources to inform its national plan and target programmes, he explained. At the facility level, data were captured by district information officers, while data from surveys were also fed into modelling software (with support from UNAIDS). The current national HIV plan was informed by these data, which made it possible to accurately understand the distribution of new HIV infections and to target interventions. UNAIDS-supported modelling also supported the targeting of high-incidence and high-need locations. Other surveys were guiding a stronger focus on key populations, he said, and were monitoring access and affordability of services for those populations.
20. Data management processes were experiencing some challenges, however. There was a shortage of technical human capacity for data management, monitoring and evaluation, data analysis and reporting; a lack of resources to finance equipment, household surveys and recruitment of personnel; poor harmonization of data systems and donors' different reporting requirements. More technical, financial and human resources were needed to enhance data management and modelling skills at council level, and databases had to be harmonized at all levels, he said. The use of the data should be built into the routine workflows at district level and population-based surveys should be mainstreamed to reduce reliance on donor support, he told the meeting.
21. Ngqabutho Mpofu, Head of Advocacy and Communications for the Treatment Action Campaign and member of the Ritshidze Project's technical team in South Africa, spoke on the role of community-generated data. He described the Ritshidze project, which monitors service provision at health facilities. Poor-quality services were a problem in South Africa and neighbouring countries, he said, and key populations faced many barriers when accessing HIV services. PEPFAR data showed that about 510 000 people had stopped HIV treatment or died in 2019. Since then, COVID-19 had caused a decline in visits to health facilities.
22. Community-led monitoring projects like Ritshidze were developing new tools for collecting, analysing and visualizing data. Ritshidze monitored more than 400 facilities in 29 districts in 8 of South Africa's 9 provinces, Mr Mpofu explained. Quarterly monitoring data were made available at facility, district and national levels. The data highlighted staff shortages, long waiting times, infrastructure problems and lack of cleanliness, poor staff attitudes (though the situation differed from place to place), inconsistent protocols for missed appointments, stockouts and unfriendly services. Many staff also had poor understandings of viral load testing and there were issues with ensuring safety and confidentiality of index testing.

23. Mr Mopfu said the project was engaging the health-care system at different levels with its findings—and to good effect. Over 18 months, waiting times had been reduced from 6 to 4 hours, there were fewer complaints about poor staff attitudes, and more clinics were screening for intimate partner violence and gender-based violence. This showed the value of having communities as coproducers of knowledge, he said.
24. Andrew Grulich, Head of the HIV Prevention Programme at the Kirby Institute in New South Wales, Australia, discussed the use of routine and survey data to identify gaps in service uptake and to achieve greater equity in prevention responses. He began by describing New South Wales' HIV epidemic, which was concentrated mainly among gay men and other men who have sex with men (who accounted for more than 70% of new diagnoses). Describing the main data sources used to analyse the epidemic and response trends, he said the data were disaggregated by age, place of residence and country of birth, and were cross-referenced with census information on cohabiting male couples. Clinical sentinel surveillance systems at clinics and behaviour surveys also provided valuable data.
25. Mr Grulich summarized some key findings. After being stable for almost two decades, new HIV diagnoses had fallen by 25% in 2015–2019, though mainly among Australian-born men. HIV incidence appeared to be increasing among newly arrived men, and new diagnoses were declining the least among younger men. Testing and treatment data showed few differences by country of birth. There had been a major change in the uptake of pre-exposure prophylaxis (PrEP), which increased steeply in 2015–2019 from almost zero to 60–70%. Data pointed to PrEP uptake being a major factor driving declining HIV incidence, against a background of high levels of HIV treatment. The disparities in HIV diagnoses could be explained by different degrees of access to HIV testing and PrEP, Mr Grulich explained. In light of the data analysis, the latest New South Wales HIV strategy was focusing especially on reaching recently arrived, overseas-born gay men and other men who have sex with men, those younger than 15 years and those living outside central Sydney, he said.
26. Chewe Luo, Associate Director, Programme Division Chief, HIV Section, UNICEF, discussed the progress made in validating the elimination of mother-to-child transmission, expanding coverage of antiretrovirals (85% in 2020) for women living with HIV, and the corresponding steep drop (53% since 2010) in new HIV infections in children. However, 150 000 new infections still occurred each year in children, almost eight times more than the level that would put the world on-track to eliminate vertical transmission of HIV.
27. Closer analysis of data, particularly a "stacked bar" analysis, was revealing where the response had to improve, by showing the main sources of new infections in children, Ms Luo explained. The analysis also showed different patterns in different regions. For example, in western and central Africa, most child infections were via women who had acquired new HIV infections during the pregnancy or breastfeeding period. The information was being used to improve programmes, she said and shared analysis of the improvements that could be made by retaining all women living with HIV on treatment, providing PrEP to pregnant women, or providing all HIV-positive pregnant and lactating women with ART. Countries could now focus their programmes with much greater precision to have the largest impact on the factors that lead to continuing new HIV infections in children.
28. Ms Luo concluded by summarizing the six main intervention areas for preventing mother-to-child transmission of HIV: prevention services for women and girls; timely engagement in antenatal care; timely access to HIV testing; timely ART initiation; programme retention and adherence support; and services for infants at highest risk of

HIV acquisitions.

29. Speakers welcomed the segment and thanked the Secretariat for the thematic report. They reiterated the importance of comprehensive and good-quality data for determining when and where the HIV response was off-track. The collection of qualitative data on service provision and access was vital, they added, stressing the importance of community-generated data to capture the experiences of all groups. Some members shared updates on how they were improving the collection, sharing and use of data in their HIV programmes.

## **Panel 2. Leveraging data to reduce HIV-related stigma and discrimination and improve quality of life**

30. Irum Zaidi, Deputy Coordinator, Office of the Global AIDS Coordinator, PEPFAR, outlined PEPFAR support for robust routine information systems, including through partnerships with UNAIDS, WHO, the Global Fund and host governments. HIV programmes had evolved and the need for patient-centred care was now widely acknowledged. She briefly discussed examples of HIV gaps by age, sex and population and showed how disaggregated data were helping programmes identify which populations were not being reached and introduce changes to meet their specific needs.
31. Data from Zimbabwe (2016–2020), for example, showed overall improvements in knowledge of HIV status, treatment coverage and viral load suppression, but disparities were revealed when the data were disaggregated by age, sex and population. Treatment services had been built mainly around antenatal services and had to be adapted to also meet the needs of men, she told the meeting. She highlighted the value of combining timely census data with routine HIV information to reveal in greater detail the gaps and disparities and the reasons for the disparities. However, robust data for key populations remained very rare; those data sources had to be developed, she urged.
32. Ms Zaidi discussed the Nigeria National Data Repository, which includes individual-level data from 36+1 states across the country, gathered at 1,650 health facilities from over 1.5 million people receiving HIV services. The data helped reveal who was not serviced, the quality of services, trends in retention in care and treatment adherence, and more. The information could also be triangulated with data from community-led monitoring to discover people's experiences when accessing services, she said. Triangulated data could reveal factors besides age, sex or location that were affecting people's health and access to services. These important data had to be made available but also had to be managed carefully to protect people's privacy and confidentiality.
33. Sairat Noknoy, Chief of HIV Treatment and Care in Thailand's Ministry of Public Health, discussed the use of data to reduce HIV-related stigma and discrimination in health-care settings. Thailand was celebrated for its success in HIV prevention and treatment, she said, but stigma and discrimination were major barriers for accessing treatment. She recalled how a 2009 study had shown that HIV-related stigma and discrimination were prevalent in Thai society, and how this led the Thai Government to work with academia, civil society organizations and donors to develop a programme to reduce stigma and discrimination.
34. Ms Noknoy described that process. People's experiences of stigma and discrimination at health-care facilities were tracked and a tool for systematically monitoring stigma and discrimination was implemented in 2015. Stigma and discrimination were also

tracked in the general population (via questions added to national surveys) and among key populations (via integrated biological and behavioural surveys in 2016). The collected data were used to develop interventions to reduce stigma and discrimination in health-care settings. This started with a pilot programme in six hospitals (2016) which was expanded to 48 hospitals in 2018 before being rolled out nationally in 2019, along with the launch of an e-learning programme and a national partnership to eliminate all forms of discrimination. A self-stigma reduction programme was piloted among key populations in 2017 and then piloted at three hospitals in 2018.

35. Surveys of health personnel and PLHIV tracked changes in stigma and discrimination at health-care facilities. The data were used at local and national levels to advocate for interventions and develop activities in participating hospitals. The data showed that attitudes and behaviour of health personnel had improved slightly and the experiences of PLHIV had improved.
36. Domingos Duran, Head of the Therapeutic Intervention Division in Portugal's Directorate for Intervention on Addictive Behaviours and Dependencies, discussed how data were being used to inform and reduce HIV-related stigma and discrimination in his country. He said Portugal's decriminalization of drug use had faced strong opposition. In the late 1990s, drug injecting had been a major public concern, with an estimated 150 000 people using injectable drugs and new HIV infections rising steeply in this population. After the decriminalization of drug use, new HIV infections declined quickly to negligible levels among people who inject drugs by 2014. Hospital admissions of people who inject drugs also decreased, as did overdose-related deaths. Specific patterns of drug use also changed. A drop in the use of heroin from 2011 onward correlated with a drop in HIV infections among people who inject drugs. In summary, the data showed clearly that decriminalization had led to the opposite of what critics had predicted.
37. Speaking from the floor, participants acknowledged the importance of data, but warned that they also carried possible risks. They highlighted concerns about how data were collected and used, including through genomic surveillance, against key populations. Specific safeguards and protections must be introduced and enforced, they insisted.
38. Speakers acknowledged UNAIDS' efforts to make HIV data widely available through the Data Hub, the AIDSinfo website and other channels. They emphasized the need for monitoring and evaluation systems that can accurately track progress and that combine government- and community-generated data. The latter were not an add-on, they reminded, and should be a pillar of HIV data systems. Community-generated data needed to be designed and driven by communities, they said, which required resources, capacity and training. A member noted that the Background Note (UNAIDS/PCB (49)/21.34) references to sex work could have further highlighted the associated risks. Regarding the decriminalization of drug use, the member said that it created situations conducive to drug use and increased risk behaviours and pressure on medical services.

## Conclusions and the way forward

39. Ms Hader presented the closing remarks. She thanked the organizers, presenters and other contributors to the thematic segment and noted that understandings were still evolving about what works and how to solve problems in ethical ways. Programmes were still figuring out how to combine "big" and "small" data, and how to do so without compromising privacy, safety and confidentiality, she explained. COVID-19 had highlighted the need for timely, accurate and disaggregated data, for properly understanding and using the data, and for building protections into data systems. The

tasks that lay ahead for the HIV response included challenges that also applied to the COVID-19 response and to preparing for and confronting future pandemics, she said.

**Draft decision points:** the PCB is invited to:

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